

Ordinary and extraordinary treatment

An argument that has appealed particularly to Catholic theology involves putting moral weight on the distinction between ordinary and extraordinary treatment (9). Extraordinary treatment is not obligatory and its extraordinariness consists in its involving great costs, pain or inconvenience, or in being a great burden to the patient or others, without a reasonable hope that the treatment will be successful. Almost all the terms of this distinction cry out for analysis, but where resources are not scarce and not competed for by needier or worthier patients, it seems that the crucial issue is whether just staying alive is a 'success'. So long as it is reasonable to suppose that it is, and to suppose this I think we must judge it to be in the patients' interests to live, then it seems difficult to justify the withholding of even extraordinary treatment. For to come to the conclusion that it is in the patients' interests to live we must believe that the pain, costs, inconvenience and burdensomeness of treatment to the patients are compensated for by their being alive. And so if it is in the patients' interests to live it would require a very strong accumulation of pain, distress, costs or whatever to *others* or to society, to justify the patients' being sacrificed to secure their, or society's, freedom from such burdens.

It comes down to this: unless it is clearly in the patients' own best interests to die, then we cannot be justified in bringing about their death by either active euthanasia or by selective non-treatment, unless we can show either that something more important than their lives can be gained by their demise, or that their lives are somehow less important than other human lives and so permissibly sacrificeable to protect values less significant than human life. This may well be true of young children whether handicapped or not. There is a good case for treating young children as having much the same sort of status as a fetus and for thinking about questions of their life or death in much the same way that we think about the permissibility of abortion. That however is another argument (10), (11). At least we can see that the extraordinariness of the treatment required does not play a role in the determination of these issues.

We can also see that the corollary is true, that if it is in the patients' own best interests to die and, as with handicapped children, they cannot be asked whether or not they accept this assessment, then we can conclude that it would be right to bring about their deaths. If this is so then to do this by selective non-treatment is worse than to do so by quick and painless killing. Worse because it inevitably involves more of the very pain and distress, which made an end to life desirable in the first place. Worse also because it may involve both a self-deception and a, perhaps unwitting, deception

of others which prevents a clear view of, and so clear judgments about, what is happening.

References

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Commentary I and reply

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Dr Harris's article is a very interesting contribution to the ethical aspects of treating severely handicapped infants. Like so many 'lay' people without any personal experience of the conditions we discuss he naturally looks at the situation from a very different angle from those of professionals caring for such children, of the parents, and of the children themselves once they are old enough to recognise their own condition adequately.

Dr Harris also lives in a vacuum which excludes the practicalities of solving or attempting to solve a desperately difficult situation. He may well be right in his implied recommendation that active euthanasia, that is, 'mercy killing', is a more humane, quicker and more logical solution than selective non-treatment—another name for letting nature take her own course. Nevertheless, it would be wrong to assume as he seems to assume that active euthanasia would be less traumatic, either to parents or to professional staff who may be expected to carry this out. The killing may be quick and painless, but the aftermath of thoughts and guilt complexes in the parents and persons involved is likely to be much worse than caring for the baby in a humane way until it dies. There is no question of self-deception or hypocrisy here. Furthermore, though many parents do express a wish, when their infant is very handicapped, that the doctor should put an end to the life painlessly, this is illegal and I would strongly disagree with any suggestion that we

ought to carry out an illegal act however logical it may seem to be to some. Even if it were legal I should certainly never do it. Nor can I conceive of any legislation which could draw up a list of criteria as to who should be killed for the sake of mercy and who should carry out such an act.

Dr Harris also implies, mistakenly, that if a baby with severe spina bifida is treated he will live, and if he is not treated he will die. Before any treatment for spina bifida was practised well over 90 per cent died in the first year of life irrespective of the degree of their handicap (1). No exact data about the kind of lesion and the degree of abnormality at birth exists from those days but one can readily surmise that the most severely affected died, perhaps nearly 100 per cent, whereas those mildly affected lived in the absence of any treatment.

All the evidence shows that the very severely affected babies, who today are selectively not treated, had a very high mortality. Even very recently when every baby in the 1960s was treated, well over half of those who would not be treated today died without ever leaving hospital. If one takes the whole population, as opposed to results from individual hospitals with very high survival rates, one finds that less than half of all babies born with spina bifida survived to three years of age. For example, in the London survey by Spain (2) the less severely affected tended to survive and most of the others died often after very many operations and other methods of treatment which are both painful, distressing and extremely expensive.

It is true that one cannot get the consent of the baby to non-action, but it is equally true that one cannot get their consent for all the major operations and procedures which have been carried out on them. Until recently it was extremely rare for parents to be consulted about what was proposed for the babies, except in the vaguest terms, and they were almost never given an indication of what kind of life their baby faced and what kind of life the family would be subjected to on the baby's survival. In fact, once parents of a severely affected child know what kind of life their baby faces and what its handicaps will almost certainly be, almost 100 per cent are against treatment, and would be even if the doctor were to try to persuade them to agree to an operation and other treatment. It must be realised that no doctor in this country can operate on a child without the parent's written agreement, and nobody would try to force such parents, say, by court action to allow the baby to be operated on when the results are bound to be highly unsatisfactory and damaging to the baby. No court can force an individual doctor to operate against his better judgment.

The survival of extremely affected individuals has a major effect on family life. Mental breakdown in the parents is not rare, and sometimes leads to suicide. The divorce rate and family breakup is much higher than in the general population. The

brothers and sisters of the handicapped child suffer and there are major financial implications for a family, even when treatment is free.

My approach to these matters is widely supported. Thus the reaction I have received from parents to my point of view, which was very adequately discussed and argued on television and in other media, was almost universally favourable. Branches of spina bifida associations have expressed their support for taking such a stand even though most parents of living handicapped children, naturally, wish that everything be done for them to improve the quality of their life, and this is being done without hesitation. I have had countless letters of support from individuals or societies. Here is one example:

The Committee would like it put on record that, at that meeting, which had an audience of 200 people, comprising doctors, nurses, midwives, social workers, parents of spina bifida children and people connected with families having spina bifida children, an outstanding majority voted in favour of your method of selection; that is to say that babies should, on the first day of birth, be assessed and selected for treatment or non-treatment.

(Extract from letter from the Nottingham and District Association for Spina Bifida and Hydrocephalus, dated 18 February 1972)

My point of view has been supported by churchmen in the highest offices from various Christian demoninations and other religions in public. The Ethical Committee covering my hospital 'unanimously supported the ethical correctness of Dr Lorber's policy'. Thus there is widespread support within our society for the policy of selective non-treatment.

It must be understood that babies must be very carefully assessed by real experts of this condition so that the decision reached is correct. And it must be stressed that all babies who live untreated must be given all nursing and medical care and treatment necessary to make them comfortable, even though nothing is done to prolong their lives. I know that a policy of selective non-treatment is a very long way from ideal and may be attacked on principle for many reasons, but we live in a practical world and I believe that this is the only practical and humane way in which one can deal with these virtually impossible situations where truly good solutions do not exist.

It is all the more heartening that recent methods of antenatal detection of spina bifida have substantially reduced the number of severely affected babies born today, so that such difficult decisions about non-treatment are less and less common. Once we have truly preventive methods, and there are indications that this may be the case in the not too distant future—then this painful phase in the

history of treating severely affected babies will prove to be a very short one. Everyone will be glad when it is over.

References

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Commentary 2

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It is a pretty scene: a doctor deciding that it is in a child's best interests to die. Similarly is Dr Harris making the same decision, though in a more abstract and generic kind of way. The way you make the decision is: see what you'd think of a proposal that you should swap your life for this (sort of) life. If the idea is horrid, if you'd rather die, then to die is in the best interests of the being you're considering—not a medical decision of course; it is just done by imagining a proposition. What a lot of creatures you have reason to kill under that method of reckoning! They have only to be incapable of consent, and you'd have a *sufficient* reason.

'But no!' it may be replied, 'It's got to be your business, and it is the doctor's business, for these are his patients.' To repeat, this is not a medical decision, even if in making it the doctor refers to some medical facts. In the case in hand, it is a reversion to the ancient human tendency to kill unwanted children. This is cloaked in the language of moral concern. But it is a decision about the worthwhileness or value of a life, and medicine tells us nothing about that. Dr Lorber happened to be in a position of *power* because of his profession. But essentially he was no more justified in deciding to kill babies by neglect and starvation than I would be entitled to kill some incompetent who fell into my hands, and who I thought would be better off dead.

As Dr Harris reports the matter, Dr Lorber aimed at the death of the children; it was to be accomplished by non-treatment and sometimes by starvation. As Dr Harris indicates, if you are aiming at someone's death it hardly makes a difference whether you bring it about by omission of treatment and failure to feed, or if you do it more actively. The infamous thing is to aim at the patient's death.

Clearly it isn't enough for Dr Harris to have

people killing (on purpose) by omission; he wants to get them doing it by commission. Now while there isn't much difference in the wicked intent (the only one I can see is that in adopting the method of neglect you leave it longer open to change your mind), yet there is *some* difference about what you do.

For wilful starvation there can be no excuse. The same can't be said quite without qualification about failing to operate or to adopt some course of treatment. There is a question here which needs discussion: whether, when and why a doctor has an obligation to do anything for someone? I mean: to do anything in the way of medical treatment. Has he such an obligation simply because of (say) the existence of a National Health Service, and because he belongs to it? Can't a doctor sometimes say: 'I do not want to treat this patient, I actually don't want him as a patient of mine?' Can he sometimes, or can he never, say the following?: 'I do not want to prolong this person's life by taking medical measures to do so. I am not saying it is *better* not to; I would say nothing against another practitioner who might want to. But I don't want to. And I don't have to.'

This is a deep and important question of medical ethics, which has perhaps been discussed. I have not seen discussions of it.

I think I perceive in the writing of Dr Harris a blindness to *such* a possibility of non-treatment. This may be because of an assumption that the doctor into whose hands such people have somehow come, is ethically obliged *either* to aim at their cure *or* one way or another to seek for them not to be cured. Perhaps the assumption (which I am attributing to Dr Harris) should be limited to people who will die of their sickness if medical measures are not taken. Either way such an assumption seems absurd.

Suppose we consider a different assumption: a doctor into whose hands sick people come is *ethically obliged (if he can) to treat them with a view to curing them*. This Dr Harris does not believe; but I think he believes it is true *except* in the case where the doctor would justifiably aim at his patient's death. But, forgetting about *that* exception, I am still disposed to think the assumption is *not* universally true, though setting limits to it is not easy. Of course, a doctor might not allow people to 'come into his hands', and it is another question when he is entitled, or not entitled, to refuse to let this happen. But if they somehow *have* come into his hands—by being born to patients, for example—that is where there is need to examine the particular assumption I have mentioned.

Another presumption I seem to detect in Dr Harris's writing, is the presumption that action and omission are everywhere equivalent. Philosophers, I fear, often seem to think that *either* omission is never equivalent to positive action that has the same